



William F. Weld  
Governor

David P. Forsberg  
Secretary

David H. Mulligan  
Commissioner

*The Commonwealth of Massachusetts*  
*Executive Office of Health and Human Services*  
*Department of Public Health*  
*150 Tremont Street*  
*Boston 02111*



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MEMORANDUM

TO: Leominster Environment and Health Working Group

FROM: Suzanne K. Condon, Director *SKC*  
Bureau of Environmental Health Assessment

RE: Attached Report of the Expert Panel

DATE: May 14, 1992

Yesterday I received the attached report summarizing the findings of the expert panel which we convened to review the medical records of the reported autism cases. The report on the industrial history is also nearly complete and I believe it would be important for the working group to meet over the next few weeks to discuss what the next steps are in this investigation.

Please contact Dr. Ngozi Oleru at (617) 727-7170 at your earliest convenience in order to schedule this meeting.

Thank you for your continued assistance in this important public health investigation.

cc: Marianne Prout, M.D., M.P.H.  
Robert S. Knorr, Ph.D.

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REPORT OF MEDICAL RECORD REVIEW  
LEOMINSTER AUTISM INVESTIGATION EXPERT REVIEW PANEL  
MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH  
BUREAU OF ENVIRONMENTAL HEALTH ASSESSMENT

Introduction

The Bureau of Environmental Health Assessment, Massachusetts Department of Public Health is in the process of investigating a suspected high prevalence of autism in the community of Leominster, Massachusetts. In the context of that investigation, names of children whose parents lived in Leominster between 1960 and present were identified.

Three sources for obtaining these names were utilized by the MDPH in conducting this investigation : private citizen reports, survey of pediatricians and otolaryngologists in the Leominster area, and the Special Education Program of the Leominster Public Schools.

This process was variable in its success. Citizen reporting identified 31 children, and 24 families responded to requests for medical information regarding these children. The public schools identified 10 children from current records, two of whom had not been identified by citizen reporting. Requests for medical records were answered in both instances. Of the 51 physicians contacted, none identified cases that had not already been identified through citizens or schools.

Thus, 26 sets of medical records were available for review. The staff of the BEHA/MDPH made strenuous efforts in recontacting families who had not responded to initial requests for records, and are to be commended for this effort.

This panel was only able to review those cases in which families had complied with requests for information. The lay press has been filled with recent reports regarding number of " cases " of autism " identified " in Leominster. These numbers have the potential to cloud the issue of this review. In a society that guards the rights of individuals to control access to their medical records, a governmental inquiry is limited by the cooperation of citizens to make sensitive data available for review.

By its nature, this report can only review those case records made available to this panel.



### The Charge

In an attempt to sort out the issue of diagnosis in these 26 cases, the BEHA/MDPH sought experts in speech/language pathology, communication disorders, psychology, behavioral and developmental pediatrics, child neurology, and epidemiology outside the agency to review these records. That panel, which prepared this report, was given the following charges :

1. Given the process the MDPH has gone through and the difficulties surrounding this issue, the panel was asked to help determine whether all potential cases of autism had been found, and if not what should be done.

2. The panel was asked to determine if the prevalence of autism is in fact unusual.

3. The panel was asked to conduct a standard review of available medical records and based upon this review determine whether the children reported to the BEHA/MDPH have autism or some related disorder with a potential common etiology.

4. The panel was asked to make recommendations to the BEHA/MDPH regarding further investigatory activities if it decided that the prevalence of autism in Leominster was indeed elevated.

5. The panel was asked to prepare a report with its findings.

The panel met for the first time on 11 February 1992, at which time it was given records for review. At that time, the panel met in caucus and determined a methodology for its investigation, described below. The panel next met on 6 March 1992, and completed its review of records. This report was subsequently prepared.

### Methods

The panel discussed various methods of chart review, and decided upon the following. All charts were read by all members of the panel between the first and second meetings of the panel. Each chart was assigned a primary and secondary presenter. At the time of the second meeting, the primary presenter gave a brief overview of the case history as obtained from the records. S/he then answered a series of questions the panel had agreed upon as operational ways of meeting our five charges. The secondary reviewer then offered any other pieces of information s/he felt the primary presenter had not emphasized, and the entire panel then discussed the case. The panel then made a collective answer to the questions outlined, and the chair recorded this on a data form.

It should be noted that the panel operated with remarkable





unanimity , and was able to reach all decisions by consensus.

The questions we posed ourselves are included as an appendix to this report. We specifically asked if the child had autistic disorder or pervasive developmental disorder, not otherwise specified, using the Diagnostic and Statistical Manual, Version Three - Revised, of the American Psychiatric Association; it was the unanimous opinion of the panel that this allowed for the greatest precision in decision-making. We also looked for evidence of other specific language disorders that are often confused with the autism spectrum or pervasive developmental disorders.

We noted those charts in which insufficient information was available to make a responsible determination.

### Results

26 cases were available for review. 21 were male, and 6 were female.

In 6 instances, children clearly met criteria for autistic disorder.

In 7 cases, children clearly met criteria for pervasive developmental disorder, not otherwise specified.

In 6 cases, children quite clearly did not meet criteria for either condition.

In 7 cases, there were insufficient data available to make a decision.

11 children carried other specific diagnoses, most of which preclude a diagnosis of a pervasive developmental disorder. These included the six children who quite clearly did not have autism, and 4 of the 7 children with insufficient data for a decision. Thus, we would speculate that most of the " insufficient data " group would not prove to have an autistic disorder or pervasive developmental disorder were their records available.

For example, this catchment procedure included children with such diseases as infantile neuraxonal dystrophy, a degenerative and ultimately fatal disease that is not associated with autism.

20 of the children had been evaluated by more than one professional, according to the records. 14 had consistent diagnoses, 3 had conflicting diagnoses, and 3 had such incomplete records that no determination regarding the reproducibility of findings could be made.



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There were no convincing cases of more than one child in a family having a pervasive developmental disorder or autism spectrum disorder, despite the inclusion of three sibling pairs in this sample.

Thus, of the 26 children whose records were reviewed, 13 have a pervasive developmental disorder, that is, either an autistic disorder or pervasive developmental disorder, not otherwise specified.

This study demonstrated several difficulties of chart review methodologies.

1. One can only review the charts made available by families and health care providers. While the media mention a large number of cases, only 26 families have signed releases for review of records.

2. A general call for cases will lead to the identification of significant numbers of inappropriate cases, given the poor public understanding of autism and related disorders. As noted, children with unrelated hereditary degenerative disorders of the nervous system were identified in the call for cases.

3. Polling the physician community was not a source of previously-unidentified material.

Thus, we cannot answer the second charge. We have no idea as to the representative nature of these 26 records, and therefore cannot use them in good conscience to speak of the prevalence of autism spectrum disorders in Leominster. If these represented the bulk of the cases in Leominster, and we were to use the generally accepted figures of 4 - 5/10,000 as the prevalence of autistic disorder and 10 - 15/10,000 as the prevalence of pervasive developmental disorder, the prevalence of autism in Leominster would not seem to be excessively high. We are not yet convinced that these cases reviewed to date represent the bulk of the cases, however, and we have not calculated real prevalence rates.

The inability of the panel to document an instance of family clustering is also noteworthy. A family with more than one case of an autism spectrum disorder would be more compelling, if circumstantial, evidence to suggest a common biologic etiology. While the failure to document such clustering does not exclude such a mechanism, coupled with the number of cases in this sample that manifestly did not have an autistic disorder, it would argue against some biologic event in Leominster.



Further information regarding the cases in the study would be helpful in the seven instances noted; clarification regarding the figures cited in recent media coverage would also be helpful. An accurate census for the number of children in the base population would be essential for proper epidemiologic evaluation.

The panel finally notes the severe limitations of this methodology ( case review of " called " cases ). This has produced a large number of cases clearly outside the spectrum of pervasive developmental disorders, and has produced a large number of charts that are impossible to review. If there were a decision to embark upon further investigation, direct examination of the putative cases may be a fruitful path.

The panel

Richard Clapp  
Karen Levine  
Valerie Chase Percia  
Barry Prizant  
Leonard Rapoport  
David Urion, Chair

